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Canada

Describing the population health burden of depression: health-adjusted life expectancy by depression status in Canada

C. Steensma, MSc (1,2); L. Loukine, MSc (1); H. Orpana, PhD (1,3); L. McRae, BSc (1); J. Vachon, MSc (1); F. Mo, PhD (1); M. Boileau-Falardeau, MSc (1,2); C. Reid, MA (1); B. C. Choi, PhD (1,4,5)

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Abstract

Introduction: Few studies have evaluated the impact of depression in terms of losses to both premature mortality and health-related quality of life (HRQOL) on the overall population. Health-adjusted life expectancy (HALE) is a summary measure of population health that combines both morbidity and mortality into a single summary statistic that describes the current health status of a population.

Methods: We estimated HALE for the Canadian adult population according to depression status. National Population Health Survey (NPHS) participants 20 years and older (n = 12 373) were followed for mortality outcomes from 1994 to 2009, based on depression status. Depression was defined as having likely experienced a major depressive episode in the previous year as measured by the Composite International Diagnostic Interview Short Form. Life expectancy was estimated by building period abridged life tables by sex and depression status using the relative risks of mortality from the NPHS and mortality data from the Canadian Chronic Disease Surveillance System (2007–2009). The Canadian Community Health Survey (2009/10) provided estimates of depression prevalence and Health Utilities Index as a measure of HRQOL. Using the combined mortality, depression prevalence and HRQOL estimates, HALE was estimated for the adult population according to depression status and by sex.

Results: For the population of women with a recent major depressive episode, HALE at 20 years of age was 42.0 years (95% CI: 40.2–43.8) compared to 57.0 years (95% CI: 56.8–57.2) for women without a recent major depressive episode. For the population of Canadian men, HALE at 20 was 39.0 years (95% CI: 36.5–41.5) for those with a recent major depressive episode compared to 53.8 years (95% CI: 53.6–54.0) for those without. For the 15.0-year difference in HALE between women with and without depression, 12.3 years can be attributed to the HRQOL gap and the remaining 2.7 years to the mortality gap. The 14.8 fewer years of HALE observed for men with depression equated to a 13.0-year HRQOL gap and a 1.8-year mortality gap.

Conclusion: The population of adult men and women with depression in Canada had substantially lower healthy life expectancy than those without depression. Much of this gap is explained by lower levels of HRQOL, but premature mortality also plays a role.

Keywords: life expectancy, healthy life expectancy, mortality, health-related quality of life, depression

Highlights

- Men and women in Canada who have depression live a substantially higher proportion of their life in an unhealthy state compared to their counterparts without depression.
- This gap in healthy life expectancy between Canadians with and without depression is primarily associated with losses in quality of life.
- Emotional state, cognitive state and pain are the key attributes associated with losses in quality of life for Canadians experiencing a recent major depressive episode.
- Based on observations from past studies of the Canadian household population, the burden of depression on healthy life expectancy at a population level appears to be greater than that associated with other chronic conditions such as diabetes, hypertension and obesity.

Introduction

Depression contributes significantly to the burden of disease throughout the world, including in Canada.[1] It is estimated that over 298 million people worldwide are living with depression.[2] In 2012, about 3.2 million Canadians over the age of 15 (11.3%) reported having experienced symptoms consistent with a major depressive episode in their lifetime, while the prevalence of such an episode in the previous 12 months was 4.7% in this population.[3] Women and young people aged 15 to 24 years experienced the highest prevalence of a 12-month major depressive episode.[3]

Depression has an important impact on health-related quality of life (HRQOL), functioning, mortality due to intentional injury and health care utilization.[4-6] In

Author references:

1. Health Promotion and Chronic Disease Prevention Branch, Public Health Agency of Canada, Government of Canada, Ottawa, Ontario, Canada
2. Department of Social and Preventive Medicine, Université de Montréal, Montréal, Quebec, Canada
3. School of Psychology, University of Ottawa, Ottawa, Ontario, Canada
4. Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario, Canada
5. Injury Prevention Research Center, Shantou University Medical College, Shantou, China

Correspondence: Bernard Choi, Health Promotion and Chronic Disease Prevention Branch, Public Health Agency of Canada, 785 Carling Avenue, Ottawa, ON K1A 0K9; Tel: 613-797-3821; Fax: 613-941-2057; Email: Bernard.Choi@phac-aspc.gc.ca

addition to these direct negative outcomes, depression has also been demonstrated to increase risk for coronary heart disease,[7] stroke[8] and cancer[9] and a decline in physical functioning.[10] Potential mechanisms for the relationship between depression and physical disease include immune and endocrine dysregulation and inflammatory processes.[11] Depression has also been associated with an increased risk of mortality in general community populations, as well as in patient populations with chronic illnesses such as coronary heart disease, cancer, diabetes and stroke.[11] There are likely reciprocal effects between depression and disease, with depression being a risk factor for, and a sequela of, disease.[11]

Summary measures of population health using the Global Burden of Disease methodology[1,12–15] have ranked depression very high on the list of health conditions contributing to the global and national burden of disease, particularly in terms of losses due to disability. Major depressive episode is the second leading cause of years lived with disability globally[1] as well as in the United States,[12] the United Kingdom,[13] China[14] and Canada.[15]

Less well documented is the association of depression with life expectancy and healthy (or disease-free) life expectancy. Understanding both life expectancy and healthy life expectancy among people who have depression will help to better characterize its disease burden. A recent systematic review and meta-analysis[16] concluded that people living with a mood disorder have a mortality rate twice as high as those without a mood disorder, and potential years of life lost due to mental disorders ranged from 1.4 to 32 years, with a median of 10.1 years. Jia et al.[17] reported that adults living with depression in the United States experienced a 28.9 year loss of quality adjusted life expectancy (QALE) at age 18 compared to those without depression. Results from the few existing studies on healthy or disease-free life expectancy and depression are not consistent.[18–20] A number of these studies are restricted to older adults and thus cannot be generalized to the entire population. These studies also use a measure of functional health restricted to activities of daily living, which do not consider attributes such as pain, emotion and cognition.

The objective of our study was to estimate period life expectancy (LE) and health-adjusted life expectancy (HALE) of Canadian adults (aged 20 years and older) according to depression status. Note that the period approach to estimating LE and HALE adopted in this paper is a summary measure of population health for a given period. Period life expectancy estimates the hypothetical life expectancy of an individual were they to experience the age- and sex-specific mortality rates in a given period. This should not be confused with projected life expectancy based on modelling or cohort life expectancy based on the actual mortality experience of a specific cohort. In a similar fashion, period HALE is a hypothetical estimate reflecting an individual's healthy life expectancy were they to experience the age- and sex-specific mortality and age- and sex-specific HRQOL levels at a given point in time.

These estimates are useful to better understand the population health impact of a condition. They are also useful for informing policy and programs, and for making decisions about the relative burden of specific health conditions. Because of the varied course of depression, with both chronic and episodic cases included in the population studied, the estimates in this study should not be applied to predict the expected health course of any individual.

Methods

Data sources

To estimate HALE, several types of data are necessary: all-cause mortality rates by depression status, depression prevalence and HRQOL estimates by depression status. All-cause mortality rates for the Canadian adult population with and without depression were estimated based on a methodology that partitions rates for total population into mortality rates by disease categories using a mortality relative risk or hazard ratios and a prevalence of those categories. The methodology is described in detail in our previous study.[21]

We used data from the following three sources:

- National Population Health Survey (NPHS), for estimating mortality hazard ratios (HRs) by depression status;
- Canadian Community Health Survey (CCHS), for estimating depression prevalence and HRQOL by depression status; and
- Canadian Chronic Disease Surveillance System (CCDSS), for actual age- and sex-specific all-cause mortality rates in the Canadian population, which were then partitioned into those associated with depression and those not associated with depression, based on the mortality HR estimated using the NPHS and depression prevalence estimated from CCHS.

The NPHS is a longitudinal survey conducted by Statistics Canada of 17 276 Canadians of all ages living in households in the 10 provinces. The NPHS has a biennial follow-up spanning the years 1994/95 to 2010/11 and includes death clearance against the Canadian Mortality Database.[22] These data were used to estimate mortality HR associated with depression required for estimating all-cause mortality rates for people with and without depression. Our study population at baseline included 12 373 participants aged 20 years and older.

The CCHS is an annual cross-sectional survey, conducted by Statistics Canada, of a sample of approximately 65 000 Canadians aged 12 years and older living in households in the provinces and territories.[23] Our study used a two-year CCHS sample (2009–2010) and included 103 815 participants aged 20 years and older. We used these data to estimate the prevalence of depression, as well as to attribute depression status in estimating all-cause mortality rates (see "Analysis" section for more detail). We also obtained Health Utilities Index (HUI) scores by depression status from the CCHS. We estimated depression prevalence and HUI scores from the CCHS because the data were more recent, and the larger sample size allowed for more accurate estimation of depression and HUI scores.

We used CCDSS all-cause mortality data for the period of 2007–2009 in the study. The CCDSS collects administrative data that include death and population counts by sex and five-year age groups for all residents of all ages in all provinces and territories, who use the public health care systems. Both mortality and population size information come from provincial and territorial health insurance databases

that cover about 97% of the Canadian population. Data are collected from all Canadian provinces and territories and summarized by the Public Health Agency of Canada.[24]

Measures

Depression is measured in the CCHS and NPHS using the Composite International Diagnostic Interview Short Form (CIDI-SF) instrument. The CIDI is a structured diagnostic interview, based on diagnostic criteria from the *International Classification of Diseases (ICD-10)* and the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*, that is administered by trained interviewers. The short form of the Interview is based on a subset of CIDI questions that could still reliably reproduce prevalence estimates.[25] The CIDI-SF interview produces scores that give predicted probabilities of depression. For this study, respondents with a predicted probability of 0.9 and above were considered to have experienced a major depressive episode during the previous year. The CIDI-SF was optional content on the 2009–2010 CCHS, and not all provinces and territories chose to include this module. Estimates of depression are based on partial provincial and territorial coverage that includes five provinces (Prince Edward Island, Quebec, Saskatchewan, Alberta and British Columbia) and two territories (Nunavut and Northwest Territories).

HRQOL is measured using the Health Utilities Index Mark 3 instrument in the CCHS. The HUI is a preference-based measure of HRQOL based on responses to questions about functioning for the following eight attributes: vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain.[26] Single-attribute utility scores range from 0.0 (lowest level of functioning) to 1.0 (full functional capacity). The eight attributes are combined into an overall score that ranges from 1.00 (perfect health) through 0.00 (death) to −0.36 (the worst possible health state; from a preference perspective, some health states are considered worse than death and are consequently assigned negative scores). A change of 0.03 or more in overall HUI scores and 0.05 or more in single-attribute utility scores is considered clinically important.[27]

The HUI has been widely used, and its validity and reliability in a variety of applications is supported.[27,28] A study assessing the sensitivity to depression outcomes of several multiattribute utility indexes found HUI to be able to discriminate well between levels of severity in the two depression instruments being evaluated.[29] The HUI score is used as a morbidity measure in the estimation of HALE. Depression typically has a negative impact on the emotional state, including sustained negative affect and difficulties experiencing positive affect.[30] In order to assess whether HRQOL differences are due exclusively to changes in the HUI emotion attribute, we compared HUI scores (all ages combined) by depression status for each of the eight attributes.

Analysis

Relative risks of mortality by depression status for women and for men were approximated by HRs. The HRs were estimated by fitting sex-specific discrete-time proportional models with a complementary log-log function using the completed NPHS data. We defined people with depression as those with a high probability (0.9) of having had a major depressive episode in the 12 months prior to data collection in at least one NPHS cycle, according to a method described by Simpson et al.[31] The first episode defined a case date. Respondents were followed up for mortality events every two years and a variable for each cycle was included in the model (cycle 1–cycle 9) as a time-interval measure. The sex-specific models were adjusted by age. As the HRs were used to estimate only all-cause mortality rates associated with depression, we did not adjust the models for any other comorbidities, socioeconomic status or other determinants of health. Because of the complex sample design of this survey, we used the bootstrapping method to calculate variance and produce 95% confidence intervals (CIs) for HR.[22] Age- and sex-specific depression prevalences, required for decomposing total mortality rates by depression status, were estimated using the CCHS 2009–2010. Mean HUI estimates by age, sex and depression status were also calculated. Bootstrapping was used to generate 95% CI.[23] In our study, total mortality rates by sex and 5-year age groups were estimated from CCDSS data for the period of 2007–2009. In this study, age- and sex-specific mortality rates for people with depression and for those without depression were estimated by decomposing mortality rates for the total population following the methodology we described in our previous study.[21]

We used the Chiang method[32] to generate period (2007–2009) sex-specific abridged life tables by depression using 14 standard age groups (20–24, 25–29, ..., 80–84, ≥ 85 years). The Gompertz function was used to provide an accurate estimate of LE for the last open-ended 85-years-plus age interval in order to close the life table, as described by Hsieh.[33] The modified Sullivan method[34] was used for HALE estimation. According to this method the "life-years lived" was adjusted by the HUI.

$$L'_x = L_x * HUI_x$$

where L'_x is adjusted life-years lived in age-interval x, L_x is life-years lived in age-interval x and HUI_x is Health Utilities Index Mark 3 for people in age-interval x.

The variance of LE and HALE was estimated using bootstrap methodology. Statistics Canada's surveys provide 500 bootstrap weights for variance estimation to account for complex survey designs.[22,23] Using those weights, 500 sets of HR estimates from NPHS and 500 sets of prevalence of depression and HUI estimates from CCHS were generated and all unique combinations of those estimates used to obtain mortality rates to build 250 000 life tables by depression and sex. This allowed estimating LE and HALE variance, building CIs around point estimates and conducting z tests to determine the statistical significance of the differences in LE and HALE. The 95% CIs were built based on the normality assumption. Due to the nature of the study population (adults 20 years and older), LE and HALE results were estimated at age 20 years and not birth.

The Arriaga decomposition, or partitioning, method[35] (adapted for the Sullivan method[34]) was applied to quantify which part of HALE differences according to depression status can be attributable to differences in premature mortality and which are attributable to loss of HRQOL (morbidity). For each age group, the change in HALE between the comparison groups is partitioned into the following components:

$$\Delta HALE = \Delta MORB + \Delta MORT = \frac{L_{x_1} + L_{x_2}}{2} \Delta HUI + \frac{HUI_{x_1} + HUI_{x_2}}{2} \Delta L_x$$

where $\Delta MORB$ estimates change due to HRQOL, $\Delta MORT$ estimates change due to mortality, L_{x1} and HUI_{x1} refer to the number of years lived and HUI score respectively for those with depression for age-interval x, and L_{x2} and HUI_{x2} refer to the number of years lived and HUI score respectively for those without depression for age-interval x. (More details about how this methodology is applied to healthy life expectancy estimations can be found elsewhere.[23,36])

Results

Table 1 shows the demographic characteristics of the participants in the NPHS and CCHS, the two national health surveys that we used for this study. The prevalence of major depressive episode in our study population (2009/10) was 5.5% (6.7% for women and 4.2% for men; results not shown).

Based on analysis of the NPHS data, there were 2154 deaths over the 16-year follow-up period. Mortality risk was significantly higher for those who experienced a major depressive episode (age-adjusted HR = 1.43; 95% CI: 1.22–1.68). This significant risk persisted when we restricted analyses to women only (age-adjusted HR = 1.55; 95% CI: 1.28–1.87), while the risk for men was nonsignificant (age-adjusted HR = 1.28; 95% CI: 0.98–1.68) (data not shown).

Unadjusted HRQOL values (as measured by HUI scores) varied by age, sex and depression status (see Table 2). HUI scores were considerably lower in all age groups for men and women who had experienced a major depressive episode during the preceding 12 months compared to those who had not experienced such an episode. According to definitions of disability categories based on global HUI scores developed by Feng et al.,[37] men and women with depression experienced on average moderate disability (HUI < 0.89) at all age groups, whereas only older (≥ 55 years) men and women without depression fell into this category. Similarly, men with depression on average experienced severe disability (HUI < 0.70) at age 40 years while women experienced this at age 45 years; average HUI scores for men and women without depression did not drop below this threshold at any age group in our study.

An assessment of each of the eight HUI attributes by sex (all ages combined) showed that depression was associated with a clinically meaningful lower score (i.e. a difference of 0.05 or higher) for the emotion, pain and cognition attributes (Table 2).

Both LE and HALE for women with depression were lower than for those without depression; LE for men with depression was not significantly lower whereas HALE was (Table 3). LE at age 20 was 4.1 years (95% CI: 1.1–7.1) lower for women with depression compared to those without, whereas HALE at age 20 was 15.0 years (95% CI: 13.2–16.8) lower for women with depression. For men, the gap in LE at age 20 between those with and without depression was 2.7 years (95% CI: 0.0–5.4), whereas HALE at age 20 for men with depression was 14.8 years (95% CI: 12.3–17.4) lower. LE and HALE at age 65 were lower for both women and men with depression. Women with depression had an LE at age 65 years that was 3.2 years (95% CI: 1.8–4.6) lower and a HALE at age 65 that was 6.7 years (95% CI: 5.3–8.1) lower than women without depression. LE at age 65 years for men with depression was 2.1 years (95% CI: 0.1–4.1) lower than that of men without depression. HALE at age 65 years was 6.0 years (95% CI: 3.8–8.2) less for men with depression compared to those without depression.

An assessment of the individual contribution of loss of HRQOL and premature mortality to differences in HALE at age 20 indicated that, for the 15.0-year difference in HALE between women with and without depression, 12.3 years could be attributed to HRQOL losses and the remaining 2.7 years to mortality losses. The 14.8 fewer years of HALE for men with depression equated to a 13.0-year HRQOL gap

TABLE 1
Demographic characteristics of survey participants, NPHS 1994/95 and CCHS 2009/10

Characteristics	NPHS 1994/95	CCHS 2009/10
Age, mean (range) in years	45 (20–100)	47.5 (20–102)
Sex,[a] % (95% CI)		
Male	48.6 (48.3–48.9)	49.1 (49.1–49.1)
Female	51.4 (51.1–51.7)	50.9 (50.9–50.9)
Marital status,[b] % (95% CI)		
Married/common-law	68.3 (67.3–69.3)	65.7 (65.1–66.3)
Single/widowed/divorced/separated	31.7 (30.7–32.7)	34.3 (33.7–34.9)
Highest level of education,[c] % (95% CI)		
Less than high school	25.7 (24.5–26.8)	14.4 (14.1–14.8)
High school graduation	40.7 (39.5–41.9)	23.7 (23.3–24.2)
Post-secondary graduation	33.6 (32.5–34.8)	61.8 (61.3–62.4)
Depression,[d] % (95% CI)		
Yes	NA	5.5 (5.2–5.9)
No	NA	94.5 (94.1–94.8)
Depression[d] in at least one cycle (1994–2008), % (95% CI)		—
Yes	4.7 (4.4–4.9)	NA
No	95.3 (95.0–95.6)	NA

Abbreviations: CCHS, Canadian Community Health Survey; CIDI-SF, Composite International Diagnostic Interview Short Form; NA, not applicable; NPHS, National Population Health Survey.

[a] n = 12 373 (NPHS); n = 103 815 (CCHS).

[b] n = 12 371 (NPHS); n = 103 636 (CCHS).

[c] n = 12 347 (NPHS); n = 101 783 (CCHS).

[d] Based on responses to CIDI-SF, indicative of having experienced a major depressive disorder in the previous year. n = 3501 (NPHS); n = 48 355 (CCHS).

TABLE 2
Health-related quality of life status by sex, age, HUI attribute and depression status[a], Canada, 2009/10

	Average Health Utilities Index score (95% CI)			
	Women without depression	Women with depression	Men without depression	Men with depression
Age group (years)				
20–24	0.93 (0.92–0.94)	0.82 (0.77–0.87)	0.93 (0.92–0.94)	0.74 (0.65–0.83)
25–29	0.94 (0.93–0.95)	0.81 (0.76–0.85)	0.93 (0.92–0.94)	0.81 (0.76–0.87)
30–34	0.93 (0.93–0.94)	0.74 (0.65–0.84)	0.93 (0.92–0.94)	0.78 (0.71–0.85)
35–39	0.93 (0.92–0.94)	0.74 (0.64–0.84)	0.93 (0.92–0.94)	0.80 (0.74–0.87)
40–44	0.91 (0.90–0.92)	0.73 (0.68–0.78)	0.91 (0.89–0.92)	0.68 (0.60–0.77)
45–49	0.91 (0.89–0.92)	0.63 (0.54–0.71)	0.92 (0.90–0.93)	0.67 (0.58–0.76)
50–54	0.90 (0.89–0.91)	0.69 (0.63–0.75)	0.91 (0.90–0.91)	0.66 (0.59–0.73)
55–59	0.88 (0.87–0.89)	0.71 (0.65–0.77)	0.88 (0.87–0.89)	0.59 (0.49–0.70)
60–64	0.88 (0.87–0.89)	0.68 (0.62–0.75)	0.90 (0.89–0.91)	0.62 (0.52–0.72)
65–69	0.87 (0.86–0.88)	0.59 (0.49–0.69)	0.88 (0.87–0.89)	0.60 (0.49–0.71)
70–74	0.86 (0.85–0.88)	0.67 (0.58–0.77)	0.87 (0.85–0.88)	0.63 (0.45–0.81)
75–79	0.81 (0.78–0.83)	0.66 (0.54–0.78)	0.83 (0.81–0.85)	0.69 (0.39–1.00)
80–84	0.79 (0.77–0.82)	0.48 (0.16–0.81)	0.79 (0.76–0.82)	0.36 (−0.01–0.73)
≥ 85	0.72 (0.69–0.75)	0.52 (0.37–0.67)	0.74 (0.70–0.78)	0.44 (0.10–0.79)
HUI attribute				
Vision	0.99 (0.99–0.99)	0.99 (0.98–0.99)	0.99 (0.99–0.99)	0.99 (0.99–0.99)
Speech	1.00 (1.00–1.00)	1.00 (1.00–1.00)	1.00 (1.00–1.00)	1.00 (1.00–1.00)
Pain	0.97 (0.97–0.97)	0.92[b] (0.91–0.93)	0.98 (0.97–0.98)	0.93[b] (0.91–0.94)
Mobility	0.99 (0.99–0.99)	0.99 (0.98–0.99)	1.00 (1.00–1.00)	0.99 (0.98–0.99)
Hearing	1.00 (1.00–1.00)	1.00 (1.00–1.00)	1.00 (1.00–1.00)	0.99 (0.99–1.00)
Emotion	0.99 (0.99–0.99)	0.94[b] (0.93–0.95)	0.99 (0.99–0.99)	0.92[b] (0.91–0.93)
Dexterity	1.00 (1.00–1.00)	1.00 (1.00–1.00)	1.00 (1.00–1.00)	1.00 (1.00–1.00)
Cognition	0.98 (0.98–0.98)	0.93[b] (0.92–0.94)	0.98 (0.98–0.98)	0.93[b] (0.92–0.94)

Abbreviations: CI, confidence interval; CIDI-SF, Composite International Diagnostic Interview Short Form; HUI, Health Utilities Index.

Note: Light shading signifies moderate disability (global HUI score of 0.70–0.88); dark shading signifies severe disability (global HUI score < 0.70); no shading represents either no disability (global HUI score = 1.00) or mild disability (global HUI score = 0.89–0.99).

[a] Based on responses to CIDI-SF, indicative of having experienced a major depressive episode in the previous year.

[b] Clinically meaningful difference in attribute-specific HUI score between those with and without depression.

and a 1.8-year mortality gap (data not shown).

We found large differences between adult Canadians with and without depression in terms of the percentage of their life spent in an unhealthy state (calculated as [LE − HALE]/LE; see Figure 1). Both men and women with depression spent almost three times as much of their life expectancy at age 20 in poor health when compared to those without depression (31% vs. 12% for females and 32% vs. 11% for males). These large differences persisted across age groups: based on LE and HALE at age 65, men and women with depression were still living approximately twice as long in poor health as men and women of the same age without depression (40% vs. 19% for women and 43% vs. 17% for men).

Discussion

In this study, we found significantly lower LE at age 20 for women, and HALE at age 20 for both women and men, among Canadians reporting symptoms consistent with a major depressive episode in the previous 12 months. We found this across age groups, although gaps in the proportion of life expectancy spent in an unhealthy state were greater among men and younger age groups with depression.

Although direct comparisons with other health problems need to be interpreted with caution, we found that losses of HALE associated with depression in the Canadian adult population were larger than those observed for obesity class 2 and above,[21] and for diabetes and hypertension[28] in the same population. In addition, while those studies found a greater loss of HALE among women than men, we demonstrated approximately equal losses for both sexes.

Our results align with those of Jia et al.,[17] who reported a 28.9-year QALE loss at age 18 for adults with depression, which is substantively larger than the approximately

TABLE 3
Life expectancy and HALE at age 20–24 and at 65–69, by sex and depression status[a], Canada, 2009/10

		Years (95% CI)			
	Age group, years	Women without depression	Women with depression	Men without depression	Men with depression
Life expectancy	20–24	64.9 (64.8–65.0)	60.8 (59.0–62.6)	60.4 (60.3–60.5)	57.7 (55.0–60.4)
	65–69	22.4 (22.3–22.5)	19.2 (17.8–20.6)	19.1 (19.1–19.1)	17.0 (15.0–19.0)
Health-adjusted life expectancy	20–24	57.0 (56.8–57.2)	42.0 (40.2–43.8)	53.8 (53.6–54.0)	39.0 (36.5–41.5)
	65–69	18.1 (17.9–18.3)	11.4 (10.0–12.8)	15.8 (15.6–16.0)	9.8 (7.6–12.0)

Abbreviations: CI, confidence interval; CIDI-SF, Composite International Diagnostic Interview Short Form; HALE, health-adjusted life expectancy.

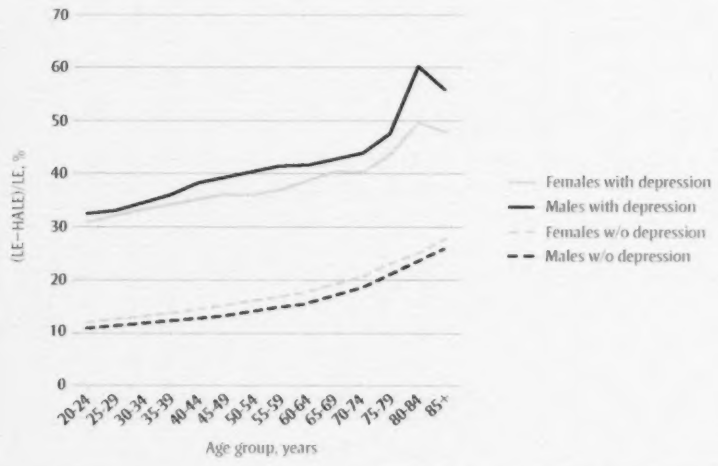
[a] Based on responses to CIDI-SF, indicative of having experienced a major depressive episode in the previous year.

15-year loss of HALE at age 20 for adults with depression that we report. This may be explained both by real differences in the health experience of the Canadian and US populations and by methodological differences between our studies. Moreover, the hazard ratio for mortality associated with depression we observed (HR = 1.43) is somewhat smaller than the relative risk of mortality of 2.08 for adults with depression reported in the meta-analysis by Walker et al.[16] Studies of older adult populations report a lower life expectancy for participants with depression. Both Chiao et al.[18] and Pérès et al.[20] report life expectancy at 65 years old as lower by approximately one year for participants with depression, whereas Reynolds et al.[19] found that life expectancy at age 70 of individuals with depression in the absence of other chronic diseases was reduced by approximately three years. While these studies found decreases in health expectancy in their participants living with depression, the magnitude of these decreases is less than we found in our study, except for male participants in the Reynolds et al.[19] study. The larger differences may be due to the fact that our measure of HRQOL included attributes not found in the Activities-of-Daily-Living measure of disability used in those three studies.

We found that a large portion of the lower HALE in participants with depression was due to lower levels in HRQOL. A comparison of each HUI attribute (Table 2) demonstrated that, although there is a clinically meaningful difference between men and women with and without depression for the emotion attribute, there are also meaningful differences for the pain and cognition attributes. Although the association between pain and depression is well documented, the relationship is complex and causal pathways are not thoroughly understood: data support both a model where depression leads to changes in the individual that increase their vulnerability to pain, as well as scenarios where pain symptoms are a risk factor for future depression.[39] Cognitive dysfunction has also been found in a large proportion of patients with depression and has been demonstrated to exist early on in the course of depression; it may even precede diagnosis.[40]

In addition to the expected lower values of HALE associated with lower HRQOL, we also found that a considerable amount of the decrease could be attributed to premature mortality. While our results found women demonstrated the largest losses of life expectancy, other studies on mortality risk and life expectancy according to depression status found that men had the greater mortality risk or loss of life expectancy.[11,17,19,20] However, most of these studies tended to focus on elderly or older adult populations that likely have a different risk profile than the full adult population. Indeed, Shah et al.[41] assessed both sex and age differences in the association of depression with mortality and found significant depression–age–sex interactions: mortality risk increased for men as age increased above 55 years while the inverse was found for women. Further study should be undertaken in non-elderly populations in order to better understand this phenomenon.

FIGURE 1
Percentage of life spent in an unhealthy state[a], by sex, age and depression status[b], Canada, 2009/10



Abbreviations: CIDI-SF, Composite International Diagnostic Interview Short Form; HALE, health-adjusted life expectancy; LE, life expectancy; w/o, without.

[a] (LE−HALE)/LE.

[b] Based on responses to CIDI-SF, indicative of having experienced a major depressive episode in the previous year.

Strengths and limitations

Our study benefitted from comprehensive data used to estimate LE and HALE across the age spectrum of adults in Canada. The survey data we used are from large, population-based samples of the Canadian household population: the NPHS allowed us to follow the mortality experience of over 12 000 adult Canadians for 16 years, a longer period than any of the other studies evaluating the association of depression status with life expectancy and/or healthy life expectancy.

Our study has several limitations. When estimating mortality risk, we only considered the first observed episode of probable depression based on the CIDI-SF and did not include depression status at subsequent follow-up. This could have led to misclassification of subjects whose depression status changed.

The definition of depression used in this study (predicted probability of major depressive episode of 0.9) is consistent with the recommended use of the CIDI-SF instrument and corresponds to reporting five to nine symptoms consistent with depression, including one of two cardinal symptoms. This measure was developed for the National Comorbidity Survey in the United States. A 0.9 predicted probability is a high threshold that likely results in more false negatives than false positives, and thus will underestimate, rather than overestimate the burden of depression in Canada.[42]

The CIDI-SF is an optional item in the CCHS and, as such, does not include responses from all Canadian provinces and territories, which may limit the representativeness of our results. We assessed the impact of the missing jurisdictions using an earlier CCHS cycle (2000/01) that included major depressive episode results for all provinces and territories. Age- and sex-specific major depressive episode prevalences from this cycle did not change appreciably when we removed the jurisdictions missing from the 2009/10 cycle, suggesting that representativeness of our study population was not affected by the missing jurisdictions. It should also be pointed out that our measure of depression, recent major depressive episode, does not adequately capture losses in healthy life expectancy specific to longer-term, chronic depression.

The CCHS is a household survey, and by excluding other populations, such as those living in institutions and long-term care facilities, it is possible that the prevalence of depression does not reflect that of the entire Canadian population. There may be differential non-response on the NPHS and CCHS: people with depression may be less likely to respond, resulting in an underestimation of the prevalence of depression. However, this would mean that our estimates are conservative, and that the true burden of depression may be higher than we report.

Our study aimed to describe the association between depression and healthy life expectancy and did not seek to understand the modifying influence of socioeconomic status or of other health conditions. However, in describing the mortality and morbidity of people with depression, it would be inappropriate to adjust for comorbid conditions. The influence on healthy life expectancy of health conditions that are comorbid with depression is unclear. While Pérès et al.[20] only found significant differences in healthy life expectancy between those with and without depression among those reporting three or more chronic conditions, Reynolds et al.[19] found large, significant differences in healthy life expectancy when comparing those with depression to those without in the absence of chronic diseases. Further study is needed to determine the impact of these risk factors and other potentially positive modifying effects, such as social participation, on healthy life expectancy.[18]

Finally, the approach to summarizing population health in this study represents the life and healthy life expectancy experience by a population at a given point in time, based on age- and sex-specific mortality and HRQOL estimates. These period estimates of life expectancy and HALE should only be interpreted as summary measures of population health, and not as the life and healthy life expectancies of any real individual.

Conclusion

This study demonstrates that, at the Canadian population level, women who have recently experienced a major depressive episode have a significantly lower period life expectancy and HALE at age 20 years than those who have not; for men, period HALE at age 20 is significantly lower for those who recently experienced a major depressive episode. Losses in HALE due to lower HRQOL are considerable and, while not as large, losses due to increased mortality risk also contribute to this difference, particularly among women. These findings demonstrate a high burden of depression in the Canadian population.

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Colin Steensma contributed to the study design, developed the first draft of the article, and critically reviewed the article. Lidia Loukine contributed to the study design, conducted all statistical analyses, wrote parts of the article, and critically reviewed the article. Heather Orpana contributed to the study design, wrote parts of the article, and critically reviewed the article. Louise McRae contributed to the study design and critically reviewed the article. Julie Vachon contributed to the study analysis and data interpretation and critically reviewed the article. Frank Mo, Michèle Boileau-Falardeau and Carrie Reid contributed to the data interpretation and critically reviewed the article. Bernard Choi contributed to the study concept and critically reviewed the article.

Data used in this study were accessed through sharing agreements with Statistics Canada and the Canadian provinces and territories. Other researchers can access Statistics Canada data through the Data Liberation Initiative of Statistics Canada.

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Developing indicators for evaluation of age-friendly communities in Canada: process and results

H. Orpana, PhD (1,2); M. Chawla, MPH (3); E. Gallagher, PhD (4); E. Escaravage, MSc (3)

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Abstract

Introduction: In 2006, the World Health Organization launched the Global Age-Friendly Cities Project to support active aging. Canada has a large number of age-friendly initiatives; however, little is known about the effectiveness and outcomes of age-friendly community (AFC) initiatives. In addition, stakeholders report that they lack the capacity and tools to develop and conduct evaluations of their AFC initiatives. In order to address these gaps, the Public Health Agency of Canada developed indicators to support the evaluation of AFC initiatives relevant to a wide range of Canadian communities. These indicators meet the varied needs of communities, but are not designed to evaluate collective impact or enable cross-community comparisons.

Methods: An evidence-based, iterative consultation approach was used to develop indicators for AFCs. This involved a literature review and an environmental scan. Two rounds of key expert and stakeholder consultations were conducted to rate potential indicators according to their importance, actionability and feasibility. A final list of indicators and potential measures were developed based on results from these consultations, as well as key policy considerations.

Results: Thirty-nine indicators emerged across eight AFC domains plus four indicators related to long-term health and social outcomes. All meet the intended purpose of evaluating AFC initiatives at the community level. A user-friendly guide is available to support and share this work.

Conclusion: The AFC indicators can help communities evaluate age-friendly initiatives, which is the final step in completing a cycle of the Pan-Canadian AFC milestones. Communities are encouraged to use the evaluation results to improve their AFC initiatives, thereby benefiting a broad range of Canadians.

Keywords: *age-friendly, evaluation, aging, community, Canada*

Highlights

- An increasing number of communities across Canada have implemented age-friendly community (AFC) initiatives. Many are ready to evaluate their activities.
- Through a comprehensive review, the Public Health Agency of Canada generated potential indicators of age-friendliness that could be used for evaluation purposes. A multiphase consultation process was used to reduce and refine a long list of candidate indicators.
- The final list includes 39 indicators across eight domains, as well as four indicators of health and social outcomes, that can support communities in their evaluation activities.

Introduction

In 2006, the World Health Organization (WHO) kick-started the Global Age-Friendly Cities Project by bringing together representatives from cities around the world who were interested in supporting healthy aging.[1] This consultation identified eight key areas of community life where communities could become more age-friendly: outdoor spaces and buildings, transportation, housing, social participation, respect and social inclusion, civic participation and employment, communication and information, and community support and health services. Canada was a key partner in developing this approach and four Canadian cities took part in consultations that shaped the development of the model. Noting that Canada's context includes a significant number of rural and remote communities, the federal, provincial and territorial ministers responsible for seniors sponsored a companion project that resulted in a document entitled *Age-Friendly Rural and Remote Communities: A Guide*.[2]

As part of its national leadership role to promote the development of age-friendly communities, the Public Health Agency of Canada (PHAC) developed pan-Canadian age-friendly community (AFC) milestones in collaboration with key partners. These milestones describe the steps needed to apply the AFC model in Canada as follows:

1. Establish an advisory committee that includes the active engagement of older adults;
2. Secure a local municipal council resolution to actively support, promote and work towards becoming age-friendly;

Author references:

1. Science Integration Division, Social Determinants of Health and Science Integration Directorate, Public Health Agency of Canada, Ottawa, Ontario, Canada
2. School of Psychology, University of Ottawa, Ottawa, Ontario, Canada
3. Population Health Promotion and Innovation Division, Centre for Health Promotion, Public Health Agency of Canada, Ottawa, Ontario, Canada
4. School of Nursing (Emeritus), Faculty of Human and Social Development, University of Victoria, Victoria, British Columbia, Canada

Correspondence: Heather Orpana, Public Health Agency of Canada, 785 Carling Avenue, Ottawa, ON K1A 0K9; Tel: 613-878-5011; Fax: 613-960-0944; Email: heather.orpana@phac-aspc.gc.ca

3. Establish a robust and concrete plan of action that responds to the needs identified by older adults in the community;
4. Demonstrate commitment to action by publicly posting the action plan; and
5. Commit to measuring activities, reviewing action plan outcomes and reporting on them publicly.[3]

Over 900 Canadian communities are currently working to become age-friendly. A number of jurisdictions and non-governmental organizations have reported that they lacked the capacity and tools to complete the fifth milestone, which is to conduct effective evaluations. In 2009, PHAC convened a meeting with key stakeholders and researchers in age-friendly communities to discuss evaluation of the AFC initiative as a whole. During this meeting, the need for indicators and data to assist community stakeholders was also identified.

In 2011, in response to mounting interest from provinces, municipalities, non-governmental organizations and Canadian researchers, PHAC undertook a rigorous process to develop a set of AFC indicators. These indicators form a menu that communities can choose from according to their unique local issues and capacities.

In this article, we describe the process undertaken by PHAC, the rationale and principles underlying the AFC indicators project and the progress to date in establishing AFC indicators.

Methods and results

Indicator identification and prioritization process

The process PHAC used to develop this set of indicators was adapted from previous, accepted methods that have been used to develop other indicator frameworks in public health.[4,5,6] Generally, the development of indicators includes establishing the purpose of the indicators; designing the conceptual framework that can be based on theory, policy and/or data;[4] and selecting or creating the indicators.[5]

The purpose of this indicator development process was to identify a menu of indicators that communities undertaking age-friendly initiatives could choose from in order to support their evaluation and monitoring activities. The overarching conceptual framework was the WHO's Age-Friendly Cities framework, which identifies eight domains on which communities can focus to support the healthy aging of their residents.[1]

An Age-Friendly Indicators Working Group was established to provide input into the development of the AFC Indicators project. This Working Group, which met regularly throughout the project, comprised officials from PHAC; representatives of provincial, territorial and municipal governments; researchers; members of non-governmental organizations and seniors.

Literature review and environmental scan

The first step was to identify potential indicators through a literature review. We searched the following databases for peer-reviewed literature published between 1990 and 2012: Web of Science, AgeLine, Cochrane Injuries Group trials register, CINAHL Database, MEDLINE, Health Source and Social Sciences Citation Index. Only English and French publications related to adults aged 65 years and older were retained. The search included the following terms and their combinations: seniors, elderly, older persons, evaluation, age-friendly cities/communities/hospitals/businesses, senior-friendly communities, elder-friendly communities, visitable housing, built environment, housing, housing modification, building codes, stairs, sidewalks, transportation, social environment/inclusion, respect, employment, volunteering, outcomes, improvement, indicators of success, falls, accidents, motor vehicle accidents, road traffic accidents, communication, community support and health services.

First, we screened titles for relevance. Articles that were clearly out of scope, for example, articles about clinical care for a specific disease, were rejected at this stage. We then reviewed the abstracts for the remaining articles and included those that reported on or implied information about indicators or measures to do with age-friendly communities. Most of these articles focussed on process evaluations or short-term outcomes of the work undertaken by communities. We found no reports of completed long-term outcome evaluations of any age-friendly initiatives. From an initial list of over 2000 documents, 23 articles were identified as relevant.

We also conducted a scan of existing AFC evaluation activities in Canada and abroad. We emailed key stakeholders in provinces, territories and selected municipalities about their activities and asked respondents to provide copies of any evaluation tools. The keywords "age-friendly" and "evaluation" were used to identify programs abroad and other relevant grey literature via the Google search engine. We retained documents from this search if they included information about existing age-friendly initiatives and/or community-based evaluations as well as information to do with indicators or measures; we found five community reports through this Internet search.[7,8] A review of our files together with the online search resulted in 20 additional documents based on our criteria.

Overall, 43 documents and articles were selected for review: 12 from the United States,[12,23] three multi-country international,[1,24,25] two from France,[26,27] two from Australia,[28,29] two from the Netherlands,[30,31] and one from the United Kingdom.[32] Twenty-one documents originated in Canada: five documents were from British Columbia,[33,37] five from Quebec,[7,38,41] four from Ontario,[9,10,42,43] one from Manitoba,[8] one from Saskatchewan[11] and five were national in scope.[44,48]

Two qualitative researchers reviewed the articles and reports, and made detailed notes on potential indicators of age-friendliness based on article contents, within each of the eight WHO-identified domains.[1] This theory-driven, or deductive, approach to collecting qualitative data[49] generated an initial list of 241 potential indicators. The two qualitative researchers worked together to develop sub-themes within each domain by grouping similar indicators together and identifying codes (or labels) that captured the common underlying concepts (see Table 1). This is an example of inductive, or data-driven, coding.[49] The research team (made up of four members with expertise in qualitative or quantitative methods as well as content expertise in gerontology and AFC) reviewed the list of potential indicators for duplication, relevance and clarity. Based on consensus, they grouped some similar concepts into a single

TABLE 1
Potential indicators for evaluating age-friendly communities in Canada and sub-themes

Domain	Initial sub-themes	Initial number of potential indicators	Final number of indicators[a]
Outdoor spaces and buildings	Walkability Actual and perceived accessibility Injuries Crime prevention	53	7 (4 with high agreement and frequent use in the literature; 3 with moderate agreement and frequent use)
Transportation	Transportation options and public transit Age-friendly streets and parking	28	6 (1 with high agreement and frequent use; 5 with moderate agreement and frequent use; 1 with low agreement but frequent use and concordance with WHO indicators. 2 of these indicators were subsequently incorporated into 1)
Housing	Housing availability Housing programs and resources Ability to age in place Housing support awareness	46	6 (2 with high agreement and frequent use; 3 with moderate agreement and frequent use; 1 with low agreement but considered to be a measure of impact)
Social participation	Engagement in social activities Opportunities for participation Accessibility of participation Opportunities	24	6 (4 with high agreement and frequent use; 2 with moderate agreement and frequent use)
Respect and social inclusion	Availability of intergenerational activities Sense of belonging	13	2 (both with high agreement)
Civic participation, volunteering and employment	Unemployment and employment Training and support Accessibility	22	4 (3 with high agreement and frequent use; 1 with moderate agreement but frequent use)
Communication and information	Assistance availability Usability of information materials	21	3 (1 with high agreement and frequent use; 2 with moderate agreement and frequent use)
Community support and health services	Primary care physician Supportive health services Community services	30	5 (4 with high agreement and frequent use; 1 with moderate agreement and frequent use)
Health and social outcomes for seniors		4	4
Total		**241**	**43**

Abbreviation: WHO, World Health Organization.

Note: The first eight age-friendly domains listed are those identified by the World Health Organization.[1] "Health and social outcomes" was added by the research team to represent the longer-term outcomes of an age-friendly community.

[a] High agreement was assigned to indicators that scored 89.5% or higher for both criteria. Moderate agreement reflected indicators that were scored at least 79.5% for both criteria but less than 89.5% for at least one. Low agreement was assigned to indicators that scored lower than 79.5% for at least one of the two criteria. These cut-offs created categories that approximated tertiles, giving equal weight to actionability and feasibility.

indicator and removed concepts deemed out of scope, reducing the list to 194. A small number of indicators that originally populated the eight domains did not fit well within sub-themes, but were considered important from a healthy aging perspective; these were grouped into a new domain, "Health and Social Outcomes." This structure was presented to the Age-Friendly Indicators Working Group for confirmation.

We also developed a list of potential criteria based on reviewed literature and shared this with the Age-Friendly Indicators Working Group. The list of criteria included the following: evidence-based, reflecting burden, representative, available, amenable to change, understandable, repeatable, important, sound, viable, direct, objective, useful, attributable, practical and adequate.[50-53] The research team identified important/relevant, actionable and feasible as the most important criteria for selecting indicators, and confirmed this with the Working Group.

Indicator prioritization through stakeholder engagement and consultation

The second phase of the indicator selection process included two targeted stakeholder consultations aimed at reducing the list of potential indicators. These

consultations were conducted using an online survey platform developed using FluidSurvey.

Consultation #1: The first consultation targeted 789 known stakeholders, including provincial and territorial representatives, municipal representatives, members of non-governmental organizations, researchers and project staff or volunteers on age-friendly projects. We identified stakeholders through existing contact lists, by the Age-Friendly Reference Group and the Age-Friendly Indicators Working Group. Respondents rated the 194 potential indicators according to their importance for measuring the age-friendliness of communities on a scale of 1 to 4, where 1 was "unimportant," 2 "of little importance," 3 "important," and 4 "very important."

A total of 191 people responded to the first consultation survey (24% response rate). All provinces were represented, except for New Brunswick, although there were few respondents from Prince Edward Island and Saskatchewan. There were no respondents from the Territories. All of the intended stakeholder groups were represented. The majority of the respondents were female (70%), replied in English (61%) and were less than 55 years old (59%). Stakeholders lived in various sizes of community: 65% lived in centres of between 1000 and 29 999 inhabitants; 9% in centres of between 30 000 and 99 999 inhabitants; and 23% in centres of 100 000 inhabitants or more.

Table 2 shows the characteristics of respondents for the first and second consultations.

The average importance rating for each indicator (on a scale of 1 to 4) ranged from a low of 2.58 to a high of 3.69. Of the top five rated indicators, three were related to enhanced health and community services and included the following:

1. Existence of programs for caregiver support (3.69 on a scale of 1 to 4) (Supportive health services)
2. Availability of low-cost food programs (3.67) (Community services)
3. Level of unmet home-care need (3.66) (Community services)
4. Existence of regulations and standards for nursing home (3.64) (Community services)
5. Number of affordable options for transportation (3.64) (Transportation options and public transit)

Based on rankings by mean importance score, the top 50% of indicators in each sub-domain were retained for further analysis. The data were also stratified by community size to examine them separately for small/medium and large communities. In the few instances where the top 50% of indicators by mean importance score were not the same in both small/medium and large communities, we added indicators to ensure inclusion of the top 50% for both of these groups. This process reduced the number of indicators to 129. A number of indicators with similar concepts were subsequently combined, reducing the list to 109.

Of the 191 respondents to the first consultation survey, 93 indicated that they would be interested in participating in a subsequent consultation survey.

Consultation #2: The aim of the second consultation survey was to further streamline the list of 109 potential indicators according to the criteria of "actionability" and "feasibility" as defined below.

For an indicator to be actionable, it can be influenced by the local or regional community, government or private sector and is likely to show change in response to action. This criterion was also used at the Age-Friendly Indicator Development Group Global Age-friendly Cities meeting[50] and by the Canadian Injury Indicators Development Team.[51] It is also similar to Daniel's[52] idea of changeability.

For an indicator to be feasible, data for it is measured (e.g. from a survey or administrative data) or described (e.g. with a photo or story) in a realistic manner without obstacles to collection or use. Such data can also be used to add richness and bring a program's results to life.[53] In addition, data collection methods are easy and realistic.[52]

Because of the response fatigue observed in the first consultation survey, the second consultation survey response choices were simplified to "yes," "no" and "don't know or no opinion." Two questions concerning the preferred data collection methods for evaluation and the design of a forthcoming PHAC-produced guide were also included in this consultation.

This second survey was sent via the online survey platform to the 93 respondents to the first survey who had indicated that they would participate in a subsequent round. Of these, 49 people responded (52% response rate). As shown in Table 2, 80% of respondents were female, and 92% responded in English. Most regions in Canada as well as a wide range of stakeholder groups were represented.

We calculated the proportion of respondents who considered a given indicator actionable or feasible. Three categories were created in order to group indicators based on actionability and feasibility. High agreement was assigned to indicators that scored 89.5% or higher for both criteria. Moderate agreement reflected indicators that scored at least 79.5% for both criteria but less than 89.5% for at least one. Low agreement was assigned to indicators that scored lower than 79.5% for at least one of the two criteria. These cut-offs created categories that approximated tertiles, giving equal weight to actionability and feasibility.

A total of 38 indicators achieved high agreement, 47 achieved moderate agreement and 24 achieved low agreement.

Indicators

Utilizing a combination of level of agreement, frequency of appearance of concept in peer-reviewed literature and grey literature, perceived concordance with the proposed WHO indicators, and whether the indicator was a measure of impact, we selected the final list of indicators (see Table 1).

All four long-term health and social outcomes indicators were retained due to their concordance with the framework proposed by WHO at the time. This resulted in a final list of 43 indicators, shown in Table 3 by domain and theme within each domain.

Respondents were also asked for suggestions on developing a tool or guide to evaluate their age-friendly initiatives. The following themes emerged from analyzing their input:

TABLE 2
Characteristics of respondents to consultation surveys 1 and 2 used in the process of selecting indicators for evaluating age-friendly communities in Canada

Characteristic	Proportion of respondents, %	
	Consultation 1 (n = 191)	Consultation 2 (n = 49)
Sex		
Female	70	80
Male	29	17
Missing	2	2
Age group, years		
< 55	59	37
55–64	28	35
65–74	11	17
≥ 75	1	7
Prefer not to answer	2	4
Language of survey		
English	61	92
French	39	8
Stakeholder group[a]		
Senior (≥ 55 years)	36	45
Family member or caregiver to a senior	21	21
Service provider in health or social services	11	23
Service provider in transportation, housing, or other community services	13	17
Policy or decision maker	17	28
Educator or researcher	11	23
Municipal employee	45	32
Elected official	11	11
Member or chair of age-friendly community planning group	—	47
Member of other senior-related community group	—	34
Other	16	13
Prefer not to answer	—	—
Level of experience with or knowledge of age-friendly initiatives		
No experience or no knowledge	2	2
Limited experience or knowledge	48	34
Extensive knowledge of and/or experience with age-friendly initiatives	49	62
Prefer not to answer	1	2
Province or territory		
Newfoundland and Labrador	10	9
Prince Edward Island	1	—
Nova Scotia	12	6
Quebec	39	13
Ontario	10	23
Manitoba	9	13
Saskatchewan	1	2
Alberta	5	9
British Columbia	13	26
Community size		
Small population centre, consisting of a population of between 1000 and 29 999	65	51
Medium population centre, consisting of a population of between 30 000 and 99 999	9	15
Large population centre, consisting of a population of 100 000 and over	23	32
Prefer not to answer	3	2

Note: Percentages may not add up to 100 due to rounding.

[a] Respondents could belong to more than one stakeholder group.

TABLE 3
List of indicators for age-friendly communities

	Domain	Theme	Indicator
1	Outdoor spaces and public buildings	Walkability	1. Number of rest places and distance between rest places. 2. Number of accessible washrooms. 3. Crosswalks are safe (e.g. with appropriate crossing times, mid-block crosswalks on long streets, median rest stops, good visibility). 4. Sidewalks, trails and walkways exist and are in safe condition (e.g. have smooth surfaces, curb cuts, separate bike lanes, are wide, well lit, clear of ice and snow).
		Actual and perceived accessibility	5. Public buildings have adequate access to and manoeuvrability around buildings (e.g. access at ground level, level entry, wheelchair ramps, automatic doors, wide aisles to accommodate scooters and wheelchairs).
		Injuries	6. Number of falls and other injuries of seniors (occurring in public places).
		Crime prevention	7. Availability of crime prevention strategies, courses and programs for seniors (including focus on fraud and elder abuse).
2	Transportation	Transportation options and public transit	8. Availability of a range of affordable options for transportation (e.g. public/private partnerships, volunteer driving program, park and go, shuttles). 9. Proportion (or number) of buses that are accessible, clean and with destination and number clearly displayed. 10. Bus stops/shelters are safe and accessible (e.g. with seating, well lit, covered, snow removed, close to seniors' residences). 11. Proportion of people ≥ 65 years who have access to and use public transportation.
		Age-friendly streets and parking	12. Streets have clear and appropriate street signage and lane markers. 13. Parking lots and spaces are kept clear of snow and ice.
3	Housing	Housing availability	14. Availability of affordable housing that is appropriately located, well-built, well-designed, secure and for which waiting times are short. 15. Availability of affordable multi-purpose and aging-in-place housing options.
		Housing programs and resources	16. Availability of programs for increasing accessibility, safety and adaptability of housing (e.g. hand rails, ramps, smoke detectors). 17. Availability of a resource listing age-friendly home maintenance, support and care-giving services.
		Ability to age in place	18. Proportion of people ≥ 65 years who want to remain in their current residence and are confident they will be able to afford to do so.
		Housing support awareness	19. Awareness of rent subsidy or other programs (e.g. home loans) among seniors.
4	Social participation	Engagement in social activities	20. Proportion of people ≥ 65 years who engage in social activities at least once a week (e.g. meet with friends/neighbours; take part in civic, spiritual or cultural activities; volunteer or work).
		Opportunities for participation	21. Availability of recreation and learning programs specifically for seniors (e.g. computer courses, community gardens, crafts, games, exercise classes). 22. Availability of intergenerational recreation and social programs. 23. Availability of opportunities for social participation in leisure, social, cultural and spiritual activities with people of all ages. 24. Affordability of seniors' recreation programs.
		Accessibility of participation opportunities	25. Public venues for community-based activities are accessible (e.g. adapted washrooms, a ramp to enter the building, better lighting, temperature control).
5	Respect and social inclusion	Availability of intergenerational activities	26. Availability of intergenerational family activities.
		Sense of belonging	27. Level of sense of belonging in the community.
6	Civic participation and employment	Unemployment and employment	28. Level of unemployment and employment among seniors.
		Training and support	29. Availability of support for volunteers (e.g. training, transportation, reimbursement of expenses, method of appreciation). 30. Availability of training opportunities related to the accommodation of seniors' needs in the workplace.
		Accessibility	31. Municipal buildings/meetings are accessible.
7	Communication and information	Assistance availability	32. Availability of assistance to seniors for filling out forms. 33. Availability of a live person option on telephone calls.
		Usability of information materials	34. Materials for the public are produced in large print, plain language and/or with age-friendly considerations.

Continued on next page

TABLE 3 (continued)
List of indicators for age-friendly communities

	Domain	Theme	Indicator
8	Community support and health services	Primary care physician	35. Proportion of seniors who have a primary care physician.
		Supportive health services	36. Availability of prevention programs to do with health issues that are highly relevant to seniors. 37. Availability of end-of-life support for seniors, their families and caregivers.
		Community services	38. Availability of low-cost food programs (e.g. meals on wheels, wheels to meals, food bank). 39. Availability of assistance for activities of daily living (e.g. yard work, shopping, snow removal, garbage collection).
	Health and social outcomes for seniors	Health-related quality of life	40. Level of health-related quality of life.
		Satisfaction with life	41. Level of satisfaction with life in general.
		Loneliness	42. Level of loneliness.
		Satisfaction with social relationships	43. Level of satisfaction with social relationships.

Note: The 43 indicators described in *Using Indicators in Your Age-Friendly Community Initiative* are listed here. Communities may use this stand-alone list as a menu from which to pick and choose indicators that are most relevant to their age-friendly activities.

- The tool should have clear definitions and criteria for measuring the indicators; it should be flexible to account for unique features of a community and should have more behavioural measures.
- The findings should lead to action at the community level.
- Long-term outcomes should be included.
- The cost of evaluations should not be a barrier (which raises the question of human and financial capacity for evaluation in communities).

During the second consultation survey, respondents were asked for ideas about the kinds of data collection methods that would be most practical for use in evaluating age-friendly initiatives. Fewer than 60% of the respondents rated the following as "very practical" or "practical": face-to-face interviews (54%), telephone interviews (51%), stories (58%) and photographs or videotaping (56%). All the other methods (online questionnaire, paper and pencil questionnaire, observations and audits, information gathered for other purposes, administrative data, use of secondary data analysis) were rated as very practical or practical by at least 75% or more of the respondents. The most practical methods were thought to be focus groups (100%), paper-and-pencil questionnaires (91%) and use of administrative data (87%).

Results of both consultations were summarized, translated into French and shared with all participants.

Based on feedback from the consultation surveys and guidance from the Age-friendly Communities Reference Group, a range of measures were identified as potential tools for communities wishing to implement age-friendly indicators in their evaluation activities. For each indicator, one or more of five potential approaches to measurement were identified: assessment tools, accessibility tools, existing data, program inventories and surveys. Qualitative and quantitative approaches were included. Tools and existing data were identified for communities wishing to evaluate their activities. Subsequently, a user-friendly guide, *Using Indicators in Your Age-Friendly Community Initiative*, (available from PHAC at http://www.phac-aspc.gc.ca/seniors-aines/indicators-indicateurs-eng.php) was developed to share the indicators, proposed measurement approaches and useful tools with communities.

Discussion

Note that the initial indicator lists were based on the literature on AFCs available when the review was conducted in 2012. At that time it was clear that the peer-reviewed and grey literature on AFCs had the following limitations: insufficient attention to specialized populations, such as ethnic groups, First Nations, and Lesbian, Gay, Bisexual, Transgender and Questioning (LGBTQ) populations; the heavy use of focus groups to seek community input (which may disadvantage those with mobility issues); a lack of consideration of specialized settings, such as nursing homes or hospitals; and finally, little emphasis on family cohesion and integration as key elements in community age-friendliness.

Since then, the literature on AFCs has grown considerably. As noted in the introduction, WHO initiated a process to identify core indicators for use by the Global Network of Age-Friendly Cities and Communities in 2011, shortly after PHAC initiated the project described in this article; WHO published a guide in 2015.[54] There is considerable concordance between the indicators suggested by WHO and the menu proposed by PHAC, which is not surprising as both projects informed one another and were developed in parallel. Concepts in common include walkability; accessibility of public spaces and buildings, of public transportation and vehicles, and of public transportation stops; affordability of housing; engagement in volunteer activity, paid employment, and sociocultural activity; availability of information, health and social services; and quality of life. A recent realist review of the age-friendliness of cities in the European Healthy Cities Network clustered the eight WHO domains into three groups: physical environment, social environment and municipal services.[55] Using a realist synthesis, the researchers mapped contexts; interventions; short-, mid- and long-term outcomes; and the goal of age-friendly programs. Again, the concepts identified based on existing programs using information from European cities is highly concordant with that developed through the present process, confirming our results and demonstrating transferability of our findings to other Western contexts.

Strengths and limitations

The process we describe in this article was developed to yield a set of indicators, relevant to the Canadian context, that would be acceptable and helpful for communities undertaking age-friendly initiatives. Because of this, a number of methods were adopted to ensure that the process was sound and of high quality. The initial stage, reviewing the literature and identifying potential indicators, was based on qualitative methods. The credibility, transferability, dependability and confirmability of this initial step were central to the process.[56]

- The credibility of these analyses is supported by the qualitative expertise of the research team, the research team's review of coding and the use of consensus to agree on grouping similar concepts into a single indicator.
- Transferability to countries similar to those described in the document review is likely. However, the identified indicators are not transferable to low- or middle-income or non-Western countries.
- Dependability is supported by describing our methods to identify indicator concepts using both deductive and inductive processes.
- Confirmability was supported through triangulation, by using multiple qualitative researchers during the document review process and by maintaining detailed notes during the process of identifying and reducing the initial lists of indicators.

Several factors limit the generalizability of the findings of the two consultation surveys. First, consultations were conducted with known stakeholders and may not be representative of a cross section of those with an interest in seniors and/or age-friendly work. For example, the general public was not consulted, and all stakeholders would have had some degree of familiarity with age-friendly initiatives. As a result, few respondents were aged over 75 years, and few identified themselves as belonging to a visible minority group. The most vulnerable and marginalized members of society, including those who were homeless, living at low income, living with dementia, living in institutions or without Internet access are missing from our sample.

Second, the response rates for each survey were fairly low and as a result, the final number of respondents was limited. Third, a pattern of response fatigue was identified because the proportion of missing data increased towards the end of both surveys, and a few participants commented that the surveys were excessively time consuming. Responses were visually screened for response sets (i.e. respondents entering the same response for all questions); no patterns of response set were identified.

The fact that the definitions for both criteria (actionable and feasible) included more than one concept may have confused some of those completing the second survey and caused uncertainty in interpreting the results. If a respondent answered "very actionable" to an indicator, it was not clear whether this was because they felt the appropriate level of government was involved or because the indicator was responsive to a change of policy or a new program or activity. Similarly, if an indicator was rated as "very feasible," did the respondent mean that the data were both qualitative and quantitative or that data could be collected with ease? Future consultations should separate criteria so that only one issue is evaluated per question.

Conclusion

The number of communities engaging in age-friendly projects is increasing across Canada and many are ready to conduct evaluations of their activities. There is a strong interest in identifying shared ways to measure progress towards becoming age-friendly, the fifth pan-Canadian AFC milestone. In this article, we reported on PHAC's process to identify and select potential AFC indicators. From an initial list of 241 indicators, we created a list of 43 indicators based on actionability and feasibility.

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Estimating chronic disease rates in Canada: which population-wide denominator to use?

J. Ellison, MPH (1); C. Nagamuthu, MPH (2); S. Vanderloo, MSc (3); B. McRae (1); C. Waters, BSc (1)

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Abstract

Introduction: Chronic disease rates are produced from the Public Health Agency of Canada's Canadian Chronic Disease Surveillance System (CCDSS) using administrative health data from provincial/territorial health ministries. Denominators for these rates are based on estimates of populations derived from health insurance files. However, these data may not be accessible to all researchers. Another source for population size estimates is the Statistics Canada census. The purpose of our study was to calculate the major differences between the CCDSS and Statistics Canada's population denominators and to identify the sources or reasons for the potential differences between these data sources.

Methods: We compared the 2009 denominators from the CCDSS and Statistics Canada. The CCDSS denominator was adjusted for the growth components (births, deaths, emigration and immigration) from Statistics Canada's census data.

Results: The unadjusted CCDSS denominator was 34 429 804, 3.2% higher than Statistics Canada's estimate of population in 2009. After the CCDSS denominator was adjusted for the growth components, the difference between the two estimates was reduced to 431 323 people, a difference of 1.3%. The CCDSS overestimates the population relative to Statistics Canada overall. The largest difference between the two estimates was from the migrant growth component, while the smallest was from the emigrant component.

Conclusion: By using data descriptions by data source, researchers can make decisions about which population to use in their calculations of disease frequency.

Keywords: Canadian Chronic Disease Surveillance System, denominator, census, population estimates Canada, disease surveillance, measures of disease frequency, administrative health data

Highlights

- Accurate population estimates are important when measuring the burden of chronic diseases.
- The authors calculated the major differences between the Canadian Chronic Disease Surveillance System and Statistics Canada's population denominators to find the best sources and the reasons for any differences between them.
- The unadjusted CCDSS denominator was 34 429 804, 3.2% higher than Statistics Canada's estimate of population in 2009. After the CCDSS denominator was adjusted for the growth components, the difference between the two estimates was reduced to 431 323 people, a difference of 1.3%.
- The largest difference between the two estimates was from the migrant growth component, while the smallest was from the emigrant component.

Introduction

Many countries, including Canada, Australia, France and Italy, have administrative health databases that are established and/or supported by governments that provide universal medical care.[1] Administrative health data refer to data routinely collected through the administration of health care services.[2] These data can be used for health service planning, reporting performance evaluations, clinical decision making and answering research questions.[2] Administrative data can also be used to conduct disease surveillance.[3-7] Measures of disease frequency, such as prevalence, incidence and mortality rates, can be used to describe the burden of disease among a population. With this information, policy, public health and health economics professionals can make informed decisions. Therefore, it is important that researchers choose appropriate denominators to calculate these measures. Calculations of incidence, prevalence and mortality rates are composed of the numerator and denominator. Improper selection of the total population can lead to biased estimates of the rates of occurrence of disease and death.[8] Estimates of populations are often the most appropriate estimate available of the number of people at risk for an outcome.

One source of denominator estimates is Statistics Canada. Statistics Canada conducts a census every five years and collects data from citizens (including permanent residents), non-permanent residents and their families living in Canada.[9] Most of the population self-enumerates by completing census surveys by mail or electronically.[9]

The objective of the census is to provide information about the demographic and

Author references:

1. Centre for Chronic Disease Prevention, Public Health Agency of Canada, Ottawa, Ontario, Canada
2. Department of Public Health Sciences, School of Public Health, University of Alberta, Edmonton, Alberta, Canada
3. Clinical Epidemiology Program, Ottawa Hospital Research Institute, Ottawa, Ontario, Canada

Correspondence: Joellyn Ellison, Centre for Chronic Disease Prevention, Public Health Agency of Canada, 785 Carling Avenue, 6th Floor, 623 A-3, Ottawa, ON K1A 0K9; Tel: 613-797-8721; Fax: 613-941-2057; Email: joellyn.ellison@phac-aspc.gc.ca

social characteristics of the Canadian population.[9] Estimates are then derived from the census and adjusted for under- and overcoverage.[10]

Another source for denominator estimates is the Public Health Agency of Canada's (PHAC) Canadian Chronic Disease Surveillance System (CCDSS). The CCDSS is a network of federal and provincial/territorial health insurance surveillance systems supported by PHAC. Denominator estimates are based on the number of people who hold valid health insurance at any given time during the fiscal year. The CCDSS is used to determine the number of Canadians living with chronic disease via interactions with the health care system, based on diagnostic and procedural codes; it adds to the breadth of information about disease burden in Canada. The system includes aggregate information for the following chronic diseases: diabetes, hypertension, ischemic heart disease, acute myocardial infarction, heart failure, mental illness, osteoporosis, asthma, chronic pulmonary disease, multiple sclerosis and parkinsonism.

This study is the first to compare the CCDSS denominator derived from national administrative health data with estimates of population from Statistics Canada. However, an Alberta Health and Wellness provincial-level study compared Alberta population counts, as covered under the Alberta Health Care Insurance Plan (AHCIP) Registry, and the 2006 census.[11] The study showed that the 2006/07 AHCIP Registry was underestimated by 0.0988% (3249/3 287 101) compared to Statistics Canada's estimate of population. However, as of June 2015, the AHCIP estimate was higher than those from Statistics Canada.[12] PHAC conducted a similar analysis in 2012, comparing the CCDSS denominator (fiscal year 2006/2007) and Statistics Canada's estimate of population (census year 2006), and found an overestimate for the CCDSS denominator of about 3.9% (955 358/24 258 902). However, this difference was difficult to interpret as data for Quebec and Newfoundland and Labrador were excluded for data quality reasons; Statistics Canada estimates were used instead. For Quebec, the data for Canadians without the disease were not available at the Institute National de Santé Publique du Québec (INSPQ), and for Newfoundland and Labrador the health insurance cards prior to 2008 did not have an expiration date, resulting in duplicate records in the medical care plan database.

The purpose of our study was to calculate the major differences between the CCDSS and Statistics Canada's estimate of population and to identify the sources or reasons for the potential differences between the CCDSS and Statistics Canada population denominators. Our objective was to inform researcher and analyst decisions about which estimate of population or denominator to use in disease frequency calculations.

Methods

Data sources

The CCDSS uses provincial/territorial administrative databases to track chronic diseases among Canadians.[4-7] The CCDSS was developed by linking three administrative databases with individuals' unique lifetime identifiers.[7] The three databases include the (1) health insurance registry file; (2) fee-for-service and some shadow-billed physician services file; and (3) hospital files that capture hospital-based acute care interactions through diagnostic and procedural codes.[7] These health databases were records of health care interactions for residents who are eligible to receive provincial/territorial health care.[7] The health insurance file contains demographic information, including a unique lifetime identifier, linking the three databases together.[13]

This health insurance registry also included a record for anyone who was alive and eligible to receive health care at any point in the fiscal year. Therefore, people who have died are captured in the year of their death. The federal government funds programs to provide subgroups of the population (First Nations and Inuit people, refugee protection claimants, eligible veterans, federal penitentiary inmates and serving members of the Canadian forces and the RCMP [Royal Canadian Mounted Police]) with health services and benefits that are not insured by provincial/territorial governments. These include coverage for dental and vision care, medical supplies and certain drugs.[14,15] First Nations and Inuit people still hold provincial health insurance and were captured by the CCDSS through the health insurance registry file.

Generally, members of the Canadian forces, RCMP and inmates of federal prisons[15] are not captured by the CCDSS (approximately 110 000 people per year). The CCDSS denominator counts were obtained from each province's and territory's data submissions to PHAC as of November 2015, up to the 2009/2010 fiscal year. Data from this fiscal year were used as they were the latest available at the time of analyses. The aggregate datasets were composed of residents with valid health care insurance at any point during the fiscal year and included residents who died within the same year, by disease and demographic variables, such as age and sex.

Statistics Canada's estimates of population

Statistics Canada's estimates of population are derived from census data. Although Statistics Canada aims to enumerate the Canadian population on census day by collecting data at a single point in time (a cross-sectional view of the population) the census misses and over-counts some fraction of the population (2.7%) (868 657/32 500 000).[16] Some people may not be counted because they were away during the enumeration period or lived in a collective dwelling that provides care or assistance services, while others were counted more than once (e.g. students living away from home who were enumerated by themselves and their parents).[16] This is described as under- and over-coverage.[17,18]

Statistics Canada conducts postcensal coverage studies using a representative sample of people to determine the number of people missed or counted more than once during enumeration.[19] The results of these studies are combined with the census estimates to produce current estimates of population, using postcensal and intercensal estimates.[10] Intercensal estimates are estimates of the population during the period between two censuses.[10] These adjustments render near complete estimates of population coverage.

Study cohorts

We compared the CCDSS denominator from fiscal year 2009/10 with Statistics Canada's estimate of population for 2009[20] by age group. The age-at-reference date for the CCDSS denominator was March 31 and July 1 for the Statistics Canada estimate of population. The CCDSS denominator was adjusted for the growth components (births, deaths, emigration

TABLE 1
CCDSS adjusted denominator, based on Statistics Canada methods,[23] Canada, 2009

Growth component	Adjustment	Magnitude of the adjusted result
Births[23]	379 373/3	126 457
Deaths[23]	237 138/3	79 046
Immigrants[24]	270 581/3	90 193
Emigrants[24]	52 335/3	17 445
Net non-permanent residents[24]	34 531	34 531
Migrants[24,25]	Out: (259 234 × 1.5) – In: (259 234)/3	302 440

Abbreviation: CCDSS, Canadian Chronic Disease Surveillance System.

Notes: CCDSS adjusted denominator (n = 33 779 692) = CCDSS count (n = 34 429 804) minus births (n = 126 457) minus deaths (n = 79 046) minus immigrants (n = 90 193) minus emigrants (n = 17 445) minus net non-permanent residents (n = 34 531) minus in-and-out-migrants (n = 302 440).

After CCDSS adjustment, the difference between the two denominators is 431 296 (1.3%).

and immigration) using files from census data (Table 1).[23] The CCDSS denominator data included interprovincial migration (i.e. residents who migrate between provinces and territories were counted more than once), whereas Statistics Canada's estimates of population were already adjusted for interprovincial migration, net immigration and deaths.[26]

We ran analyses using SAS Enterprise Guide version 4.1 (SAS Institute Inc., Cary, NC, USA). To illustrate the differences between the CCDSS and Statistics Canada's estimate of population, our analyses were conducted with and without the growth components for the CCDSS denominator. See Table 2 for a summary of the data definitions by source.

Statistical methods

The overall percent difference between the CCDSS denominator and Statistics Canada's estimate of population, for Canada and by province/territory, was calculated as

[(CCDSS denominator – Statistics Canada's estimate of population) / Statistics Canada's estimate of population] × 100.

To examine the largest impact on the rates, among all age groups, using both data sources, we compared diabetes prevalence, incidence and mortality rates that were calculated using the CCDSS denominator and Statistics Canada's estimate of population. We used the CCDSS data to count the number of all-cause deaths across the provinces/territories. We calculated rates for estimates of population from both data sources for the population denominator;

- Diabetes prevalence = [Total number of individuals with a case date during the capture period or prevalent cases / Total number of individuals with valid health insurance during the capture period] × 100 or Diabetes prevalence = [Total number of individuals with a case date during the capture period or prevalent cases / Statistics Canada's estimate of population] × 100
- Diabetes incidence = [Total number of incident cases / (Total number of individuals with valid health insurance during the capture period – Prevalent cases at the beginning of the fiscal year)] × 1000 or Diabetes incidence = [Total number of incident cases / (Statistics Canada's estimate of population – Prevalent cases at the beginning of the fiscal year)] × 1000
- All-cause mortality = [Total number of CCDSS deaths / Total CCDSS population] × 100 000 or All-cause mortality = [Total number of CCDSS deaths / Statistics Canada's estimate of population] × 100 000

These rates were calculated using SAS macros (pre-programmed codes), and the counts randomly rounded.[26] Mortality data for Statistics Canada's estimate of population were obtained from vital statistics files for 2009 (to match the CCDSS 2009/10 fiscal year).[27] To assess the impact of mortality rates with both sources of denominators on the life expectancy calculation, we compared the CCDSS denominator life expectancy by sex and age group for each disease tracked by the CCDSS to Statistics Canada's estimate of population life expectancy. We stratified the CCDSS data by sex and 18 standard age groups (1–4, 5–9,...80–84, ≥ 85 years). Next we created a life table for the number of people who had a diagnostic code for a disease and the number of people who did not. The Gompertz function was used to provide an accurate estimate of life expectancy for the last open-ended age interval (≥ 85), to close the life table.[28,29]

Since disease status was not available for infants younger than one year, the 2004 to 2006 sex-specific death rates for the Canadian population, from Statistics

TABLE 2
Data descriptions by source (CCDSS and Statistics Canada estimates of population), 2009

Data sources	PHAC's CCDSS denominator	Statistics Canada's estimates of population
Estimate type	Period estimate (Canadians with valid health insurance during the fiscal year)	Point in time estimate (estimate of the number of Canadians from the Census)
Inclusions	1) Deaths that occur during the fiscal year 2) Canadians who migrate in Canada during the fiscal year (double-counting)	1) A representative sample of Canadians 2) Adjustments for growth components (births, deaths, emigration, and immigration) and those missed (away during enumeration) or double-counted (students away from home)
Exclusions	Canadians covered under federal insurance	Canadians who are away during enumeration or lived in a collective dwelling, but adjusted for
Use/role	Is a companion for the CCDSS numerator (Canadians exposed to the health event are included in the denominator)	Is a companion for a numerator consisting of Canadians who were exposed to a health event

Abbreviations: CCDSS, Canadian Chronic Disease Surveillance System; PHAC, Public Health Agency of Canada.

Canada, were used to model the mortality experience of infants with and without the disease. The 0- to 1-year sex-specific death rates, used to construct the life table, represented infants without the disease. Infant death rates for the disease were unavailable. Because the 0 to 1 age group experienced a high rate of mortality, we assumed that the number of infants with and without the disease would be about the same.

Results

Our findings show that CCDSS and Statistics Canada estimates of population differ. Specifically, the CCDSS overestimates the population relative to Statistics Canada overall.

The largest difference between the two estimates was contributed by the migrant growth component (302 440), while the smallest was from the emigrant component (17 445) (Table 1). When deaths were included in the CCDSS denominator, we observed 1 081 408 more people in the CCDSS denominator (34 429 804) compared to Statistics Canada's estimate of population (33 348 396), a +3.2% (1 081 408/33 348 396) difference (Table 3).

After the CCDSS denominator was adjusted for the growth components, we observed 431 296 more people in the CCDSS denominator (33 779 692) compared to Statistics Canada's estimate of population (33 348 396), a +1.3% (431 296/33 348 396) difference (Table 1). The largest difference between the two was observed among the 85-and-older age group (+20.5%; 126 453/617 160) and the smallest among the 20 to 24 age group (−0.8%; 17 757/2 322 497) (Table 3).

By province/territory, the largest difference between the two was observed for Northwest Territories (+13.0%; 5600/42 965), whereas the smallest was for Quebec (+0.5%; 37 595/7 737 335) (Table 4). A similar pattern was observed after excluding deaths from the CCDSS denominator. However, after adjustment for the growth components, the difference was reduced to 431 296 people (Δ1.3%; 431 296/33 348 396) (Table 1).

For all Canadians, the CCDSS denominator diabetes prevalence rate (7.2%; 2 489 520/34 429 804) was 4.00% (−0.3/7.5) lower than Statistics Canada's estimate of

TABLE 3
Estimates of population by age group, Canada, 2009

Age groups in years	CCDSS denominator[a]	Statistics Canada's estimates of population[b]	Percent difference, %
1–4	1 540 368	1 464 423	5.2
5–9	1 845 877	1 798 812	2.6
10–14	2 009 792	1 972 894	1.9
15–19	2 264 299	2 250 692	0.6
20–24	2 304 740	2 322 497	0.8
25–29	2 358 661	2 348 492	0.4
30–34	2 310 455	2 258 092	2.3
35–39	2 377 282	2 297 458	3.5
40–44	2 512 797	2 480 011	1.3
45–49	2 858 523	2 787 129	2.6
50–54	2 686 876	2 573 413	4.4
55–59	2 322 492	2 215 710	4.8
60–64	1 999 094	1 888 212	5.9
65–69	1 480 822	1 406 971	5.2
70–74	1 137 703	1 080 535	5.3
75–79	947 527	909 136	4.2
80–84	728 883	676 759	7.7
≥ 85	743 613	617 160	20.5
All ages	34 429 804	33 348 396	3.2

[a] CCDSS denominator data were contributed by provinces and territories, as of November 2015 (v2014).

[b] Statistics Canada's estimates of population were postcensal (2006 Census).[20]

TABLE 4
Estimates of population by province/territory, Canada, 2009

Province/Territory	CCDSS denominator[a]	Statistics Canada's estimates of population[b]	Percent difference, %
Newfoundland and Labrador	537 862	504 141	6.7
Prince Edward Island	148 911	139 593	6.7
Nova Scotia	989 707	931 622	6.2
New Brunswick	755 910	742 506	1.8
Quebec	7 774 930	7 737 335	0.5
Ontario	13 563 855	12 928 815	4.9
Manitoba	1 239 544	1 204 232	2.9
Saskatchewan	1 067 733	1 015 590	5.1
Alberta	3 711 026	3 621 681	2.5
British Columbia	4 524 374	4 415 160	2.5
Yukon	33 745	33 342	1.2
Northwest Territories	48 565	42 965	13.0
Nunavut	33 642	31 414	7.1
Canada	34 429 804	33 348 396	3.2

[a] CCDSS denominator data were contributed by provinces and territories, as of November 2015 (v2014).

[b] Statistics Canada's estimates of population were postcensal (2006 Census).[20]

population rate (7.5%; 2 489 520/33 348 396) and 3.03% (−0.2/6.6) lower for incidence rates with the CCDSS denominator (6.4 per 1000; 218 240/34 211 564) and Statistics Canada's estimates of population (6.6 per 1000; 218 240/33 130 156). The CCDSS denominator total all-cause mortality rate (669.2 per 100 000; 230 408/34 429 804) was 3.1% (−21.7/690.9) lower than Statistics Canada's estimate of population rate (690.9 per 100 000; 230 408/33 348 396; Table 5). The life expectancy at birth was 82.9 years for the CCDSS denominator and 81.2 years for Statistics Canada's estimate of population.

Discussion

A difference between the CCDSS denominator and Statistics Canada's estimate of population is that the latter provides a cross-sectional view of the population at a specific time period (period of enumeration), whereas the CCDSS denominators have been used to provide an estimate of the population exposed, or "at risk," over an annual period. Although prevalence and incidence rates can be calculated for a single time point, it is more common to calculate these measures for a time period. Researchers should note that using different denominators may affect calculations of prevalence, incidence, mortality rates and life expectancy. For example, a military member who visits the hospital for diabetes will not be captured by the CCDSS, because military members are a subgroup of the population who are federally insured. Therefore, the most appropriate denominator to use for calculating a measure of disease frequency would be Statistics Canada's estimates. However, the CCDSS denominator is the most appropriate denominator for estimating measures of disease frequency, when using administrative data (i.e. numerator is derived from CCDSS data).

In addition, a researcher may wish to calculate the prevalence of diabetes in 2006 among Canadians. The researcher could obtain the number of diabetes cases that occurred in 2006 from the CCDSS and may decide to use Statistics Canada's estimates for the denominator (representing the total Canadian population for 2006). However, the risk of outcome for the numerator may not match the Statistics Canada estimates (may not represent this population). Or perhaps an individual with diabetes died before the 2006 census enumeration date, but was registered as a case in the data source before their death. In this scenario, this individual would be accounted for by the numerator, but not in the denominator, thereby resulting in an inaccurate estimate of the prevalence of diabetes in Canada during 2006.

In order to quantify the gaps in missing data in both the CCDSS and Statistics Canada's estimate of population, further research must be conducted on data quality of the health insurance registries and work to quantify subgroups of the population (i.e. emigrants) that are unaccounted for by either data source.

The CCDSS captures nearly the entire Canadian population through the health insurance registry. We recognize that people who move to a new province or territory during a fiscal year (interprovincial migration) and receive valid health insurance are counted twice in the CCDSS denominator, for a limited period of time.

The difference between the adjusted CCDSS denominator and Statistics Canada's estimate (431 296 people) may be attributed to the discrepancies of the valid and eligible health numbers defined in the health insurance registries, possibly due to fraud.[30] In addition, the health insurance registries can include inaccurate information about deaths, due to the time and resources required to process this information.[31] Statistics Canada has found it challenging to count Canadians who emigrate for work and who are homeless, but the number of these emigrants is estimated to be small.[32-35] Both the health insurance registries and Statistics Canada staff continue to monitor the data, looking for these issues and finding explanations and mitigation strategies for them. Small differences by age (in the younger age groups) can also be attributed to the different age-at-reference dates between the two data sources. The underestimate found by the Alberta ministry[11] could be attributed to the different methods used by AHCIP (2006 census data was compared) and Statistics Canada Demography Division (conducting the provincial-specific CCDSS denominator adjustment).

Conclusion

Our results illustrate the importance of making an informed choice when selecting estimates of population for research, as the selection can have an effect on the calculation of rates. We found that even after adjusting the CCDSS denominator for deaths and interprovincial migration, the CCDSS denominator was greater than the Statistics Canada estimate.

These findings allow researchers to compare the major reasons for the differences between the CCDSS denominator and Statistics Canada's estimate of population in order to select the most appropriate denominator for their projects and measuring disease frequency.

It is our opinion that the CCDSS denominator best represents the population at risk for events identified using health administrative data. The CCDSS denominator should be used to measure disease

TABLE 5
Diabetes prevalence, incidence and mortality rates[a] by population, Canada, 2009

Statistic	CCDSS denominator[b]	Statistics Canada's estimates of population[c]	Percent difference, %
Prevalence	7.2	7.5	−4.0
Incidence	6.4 per 1000	6.6 per 1000	−3.0
	Total (without the deaths in the populations)		
Mortality	669.2 per 100 000	690.9 per 100 000	−3.1

Notes: This study was made possible through collaboration between PHAC and the respective provincial governments of Alberta, British Columbia, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Prince Edward Island, Nova Scotia, Newfoundland and Labrador, and territorial governments of Yukon, Northwest Territories, and Nunavut. The opinions, results and conclusions reported in this paper are those of the authors. No endorsement by British Columbia, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Prince Edward Island, Nova Scotia, Newfoundland and Labrador, Yukon, Northwest Territories, Nunavut is intended or should be inferred.

[a] CCDSS counts were randomly rounded.

[b] CCDSS denominator data were contributed by provinces and territories, as of November 2015 (v2014).

[c] Statistics Canada's estimates of population were postcensal (2006 Census).[20]

frequency, as it comprises those with valid health insurance over a period. When Statistics Canada's estimates of population were used as the denominator, the exposed population was underestimated, as the census was taken at a point in time; however, people who were deceased or away at that time were included in the period prevalence numerator. Although the magnitude of the differences in diabetes rates between the two sources was small, these findings could have a slight implication on the interpretation and conclusions drawn from previous studies that have estimated prevalence, incidence and mortality using Statistics Canada's estimates of population as population denominator estimates.

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Report summary

Prevalence and monetary costs of dementia in Canada (2016)[1]: a report by the Alzheimer Society of Canada

Alzheimer Society of Canada

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Background

Dementia prevalence estimates vary among population-based studies, depending on the definitions of dementia, methodologies and data sources and types of costs they use. A common approach is needed to avoid confusion and increase public and stakeholder confidence in the estimates.

Since 1994, five major studies have yielded widely differing estimates of dementia prevalence and monetary costs of dementia in Canada:

- Canadian Study of Health and Aging, 1994[2]
- Alzheimer Society of Canada. Rising Tide: The Impact of Dementia on Canadian Society, 2010[3]
- Mental Health Commission of Canada: Making the Case for Investing in Mental Health in Canada, 2011[4]
- Economic Burden of Illness in Canada, 2014[5]
- National Population Health Study of Neurological Conditions, 2014[6]

These studies variously estimated the prevalence of dementia for the year 2011 as low as 340 170 and as high as 747 000. The main reason for this difference was that mild cognitive impairment (MCI) was not consistently included in the projections. The estimated monetary costs of dementia for the same year also varied, from $910 million to $33 billion. This discrepancy is largely due to three factors: (1) the lack of agreed-upon methods for estimating financial costs; (2) the unavailability of prevalence estimates for the various stages of dementia (mild, moderate and severe), which directly affect the amount of money spent; and (3) the absence of tools to measure direct, indirect and intangible costs more accurately.

Given the increasing challenges of dementia in Canada and around the globe, reconciling these differences is critical for developing standards to generate reliable information for public consumption and to shape public policy and service development.

Methods

In May 2015, following a review of these and other studies, the Alzheimer Society of Canada convened a panel of Canadian and international epidemiologists, health economists and policy analysts, as well as representatives from provincial Alzheimer Societies. Our goal was to provide advice on how best to estimate current and future prevalence and monetary costs of dementia in Canada. *Prevalence and Monetary Costs of Dementia in Canada (2016)*[1] is the result of this collaborative work.

Panel findings

Prevalence estimates

There was consensus among panel members that the Canadian Study of Health and Aging (1994)[2] remains the best and most reliable population data source to use for building present and future prevalence estimates.

The authors of this study derived the data from questionnaires and interviews conducted with 9008 individuals aged 65 years and older who were living in the community, and 1255 individuals living in long-term care homes. For the individuals who were interviewed, researchers then carried out clinical, neurological and neuropsychological examinations of 2914 people who had low cognitive scores, and a random sample of those with normal scores.

A team made up of a physician, a nurse and a neuropsychologist then assessed whether these individuals should be classified as having probable or definite dementia, and further determined the type of dementia. This method is consistent with the way diagnosis is currently achieved in a clinical setting, using multiple data sources and input from multiple health care professionals. Autopsies are seldom done, despite the fact that they are the most accurate means of diagnosing dementia.

Prevalence estimates drawn from health administrative data are not based on standardized clinical assessment as in the Canadian Study of Health and Aging or in autopsies.

Based on projections using the Canadian Study of Health and Aging (1994)[2] data, as of 2016 there are an estimated 564 000 Canadians living with dementia. By 2031, this number is expected to rise to 937 000, an increase of 66%. Of the current number of Canadians with dementia, more than 65% are women.

Monetary cost estimates

When estimating the present and future costs of dementia, three key factors must be taken into account:

1. perspective, which focusses on who incurs the cost, e.g. the public health care system only or society as whole, including people with dementia, their caregivers and employers;
2. scope, which is concerned with what costs are included, e.g. direct and indirect, informal and intangible costs; and
3. valuation, which involves the method of attributing a cost to dementia that would not otherwise exist.

Because the financial impact of dementia goes well beyond the health care system and takes a tremendous toll not only on those living with dementia, but also their families, caregivers and employers, the Panel recommended taking a societal perspective in estimating the economic consequences of the condition. It also recommended that the scope should include direct, indirect, informal and intangible costs, and that these costs should be compared between populations living with dementia and those without the condition.

The Panel concluded that the National Population Health Study of Neurological Conditions (2014)[6] met these requirements and provided the best foundation for projecting the monetary costs of dementia. According to this study, the combined Canadian health care system costs and out-of-pocket caregiver costs amounted to $10.4 billion in 2016. By 2031, this figure is expected to increase to $16.6 billion.

Generally, costs for people with dementia are estimated to be five-and-a-half times greater than for those who do not have the condition. Home care and long-term care are the largest contributors to direct costs. In 2011, family caregivers provided 19.2 million unpaid hours of care. This number is projected to double by 2031.

Applicability

Accurate and reliable data on dementia are particularly important because Canada's population is aging, and there is still no cure and pharmacological treatments are helpful only for limited times in the course of the condition for some patients. Evidence from economically developed countries shows that incidences of dementia may be declining because of higher levels of education, greater health awareness and in some cases better control of vascular risk factors.

Public health uses for these data include

- improving public awareness and understanding of the social and personal impact of dementia on Canadians living with the condition and their caregivers;
- documenting financial costs of care, loss of income and loss of productivity;
- providing benchmarks against which future progress can be measured and evaluated; and
- informing service planning and policy development, such as a national dementia strategy, human resources policies across workplaces, government projections and budgets.

The Public Health Agency of Canada, in collaboration with provincial and territorial ministries of health, has developed the first national case definition that will be used to consistently report the epidemiology of Alzheimer's disease and other dementias (prevalence, incidence and all-cause mortality) among Canadians aged 65 years and older. Data will be disaggregated by sex, age group, fiscal year and province or territory. Annual reporting of these data is expected to begin in 2017/18.

Conclusion

Prevalence and Monetary Costs of Dementia in Canada (2016) provides useful and more reliable information about the prevalence of dementia and its economic impact on Canadian society. It serves to help Alzheimer Societies across Canada as well as other like-minded organizations to develop awareness campaigns and other public initiatives, create new programs and services and influence policy development and service planning now and in the future.

To read the full report online, visit http://www.alzheimer.ca/~/media/Files/national/Statistics/PrevalenceandCostsofDementia_EN.pdf

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Call for papers: The food environment in Canada

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Special issue on: The Food Environment in Canada

Editors: **Robert Geneau** (Editor-in-Chief, Public Health Agency of Canada) and **Lana Vanderlee** (guest editor; Department of Nutritional Sciences, University of Toronto)

Diet is a fundamental component of health, and dietary habits are closely linked with the development of chronic disease and obesity. The ***food environment*** in which people make their food choices plays a major role in establishing eating habits and overall diet quality. Broadly defined as the physical, economic, policy and sociocultural surroundings, opportunities and conditions that influence food choices and nutrition status, the food environment can promote or impede healthy diets.

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